

DRAFT TESTIMONY PUBLIC HEALTH COMMITTEE
Monday March 17 2014

My name is Robin Schwartz and I am a board certified genetic counselor and as such provide risk assessment and genetic counseling in the UCONN Hereditary Cancer Program, as well as an teach at the UCONN School Of Medicine and have been a genetic counselor for 38 years, 27 of those in CT. Thank you Sen. Gerratana and Rep. Johnson for raising Bill 437 which I am here to support. This bill represents the major step towards ensuring that CT residents are fully aware of the credentials, level of education and training, and professional standards of the individuals who provide risk assessment and genetic counseling in our State.

Few days go by that genetic counseling isn't in the pages of the Courant, Time Magazine, and in the non-print media. A recent study (Genetics in Medicine) showed that although Angelina Jolie's article My Medical Decision in the NYT on May 15, 2014 raised awareness about inherited breast cancer, women were still unclear about what inherited cancer is, and the cancer risk surrounding being a gene carrier and even the risk for breast cancer in the general population. I for one am grateful for the increased awareness, but this at the same time points out how very important correct Interpretation of the information, technology that we possess and the implications of genetic tests must be accurately and thoroughly discussed, before our residents make medical decisions. Individuals come tot us with a variety of concerns about their "genetic" health and in the new era of personalized medicine that is developing, the need is increasing for skilled professionals. Things are changing; new tests come into the market on an almost daily basis. In addition to the usual routes of referral from primary and specialty health care providers, we are also seeing more concerning issues. In my experience, and those of my colleagues patients come to us with tests from direct to consumer companies with conflicting information about what their results mean and, perhaps even more concerning, incorrect information about their health risks. Genetic counselors can make a big difference in the lives of these individuals. Individuals may have incomplete risk assessment and therefore receive inaccurate information. When a resident has a consultation with a board certified, and hopefully a licensed genetic counselor they can be assure d that the get the full

range of genetic counseling services; that includes finding out their own risk as well as the risks of other family members and also insuring that their concerns are acknowledged, addressed and supported. We also provide counseling about addressing the concerns about other family members and find ways most appropriate to their own particular family situation to help them share results.

So thank you for providing a bill that helps provide both title protection and addresses protects our health consumers.

There are specific national standards for continuing education that we hope can be written into the legislation; being consistent with those standards would continue the recertification process as consistent with the American Board of Genetic Counseling 12.5 CEU in 5 years) In addition we would like to see that the time limit for applying for licensure be extended for new graduates as the certification exam does not take place often enough for new counselors to be in compliance; also I think we would like to see those who would be “grandfathered “in have a more limited time to apply.

We will be offering other suggestions to the committee for your consideration and look forward to working with you to address them. In summary thank you for the interest in the quest for professional licensure. I truly appreciate the opportunity to testify today.